

Approved 10/05/2004

**Virginia Genetics Advisory Committee**  
**Monday, April 5, 2004**  
**10:00 a.m. – 12 noon**

**Division of Consolidated Laboratory Services (DCLS)**  
**Room T-23**  
**600 North 5th Street**  
**Richmond, VA 23219**  
**Telephone (804) 648-4480**

**MINUTES**

**Present:** **Willie C. Andrews**—DCLS; **Lynette Bartlett**, LPN—VDH; **Joann N. Bodurtha**, MD, MPH, Chair—VCU; **Nancy Bullock**, RN, MPH—VDH; **Nancy Ford**, MPH, RN—VDH; **Sara Long**—March of Dimes Va. Chapter; **Heather Creswick** (for Virginia (“Ginny”) K. Proud, MD—CHKD); **Allison Schreiber**, MS—VCU/VDH; **Jene O. Radcliffe-Shipman**—VDH; **Ether Richardson**, LPN—VDH; **Charlie Stevenson**, MS—DCLS; **Sharon Williams**, MS, RN—VDH; **William (“Bill”) G. Wilson**, MD—UVA Health Sciences Center; **Melody Persinger Yeargin**—CHKD

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**Ad Hoc:** **Joanne S. Boise**, MSPH—VDH

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**Guests:** **Alli Salibian**—VCU/VDH; **Kim Snead**, Executive Director, Joint Commission on Health Care (JCHC); **Betty Thompson**, Parent; **Dana Yarbrough**, Parent

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**Absent:** **Joan Corder-Mabe**, RNC, MS, OGNP—VDH (ad hoc); **Mary Ann Discenza**—DMHMRSAS; **Laura Duncan**, MPH, RD—VCU; **Anil Kumar**, MD, VCU; **Kathleen M. Link**, MD—Inova Fairfax and Fairoaks Hospitals; **Walter Nance**, MD, PhD—Va. Newborn Hearing Screening Cmt; **Arti Pandya**, MD, MBA—VCU; **James (“Jim”) L. Pearson**, DrPH—DCLS; **Gwen Smith**, RN, MSN—VDOE; **Harvey Stern**, MD, PhD—Genetics and IVF Institute; **David Suttle**, MD—VDH

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Time	Item	Person	Notes/Plan
10:00 to 10:15	1. Welcome a. Introductions b. Approval of 9/29/03 Minutes ( <i>emailed 3/23/04</i> ) c. Review of Agenda ( <i>emailed 3/23/04</i> ) d. Membership (revised 3/23/03): Circulate list for corrections. ( <i>emailed 3/23/04</i> )	a. J. Bodurtha b. J. Bodurtha c. J. Bodurtha d. N. Ford	1. Welcome a. Completed. b. Approved as written. Note: Final minutes are posted on the VDH Minutes Calendars Web site: <a href="http://www.vdh.state.va.us/minutes/minutes.asp">http://www.vdh.state.va.us/ minutes/minutes.asp</a> c. No new items. d. Circulated for corrections.
10:15 to 10:20	2. House Joint Resolution 164. Infant screening program for metabolic disorders; joint Commission on Health Care to collect data. ( <i>emailed 3/23/04</i> )	Kim Snead, Executive Director, JCHC	2. HJR 164 overview provided; will be presented at May 4 JCHC meeting. <b>Plan</b> a. <b>K. Snead</b> will contact <b>W. Andrews</b> for VaGAC advice, review, etc. (e.g., via VAGAC Newborn Screening Subcommittee MS/MS Work Group or new Work Group).
10:20 to 10:45	3. Updates: Agencies, Organizations, Grants a. VDH: Virginia Genetics Program b. VDH: Virginia	a. S. Williams b. J. Shipman c. J. Pearson d. K. Meister e. J. Bodurtha	3. Updates a. VDH: VGP (1) RFP for Genetic Clinical Services in Northern Virginia for Perinatal Services has been initiated and closes on 4/9/04.

	<p>Sickle Cell Awareness Program</p> <p>c. DCLS</p> <p>d. VDH: CDC Grant “Va. Congenital Anomalies Tracking and Prevention Improvement Project”</p> <p>e. VCU: MOD Grant “Genetic Services and Education-Assessment of Needs”</p> <p>f. EVMS: CDC Grant Application “Genetic Services for Infants with Congenital Hearing Loss in Va.”</p> <p>g. MOD: Organization and Advocacy</p> <p>h. DMHMRSAS: Part C of IDEA: Infant &amp; Toddler Connection of Virginia</p> <p>i. DOE</p> <p>j. Other Updates</p>	<p>f. V. Proud</p> <p>g. S. Long</p> <p>h. P. Dewey and D. Yarbrough for M. Discenza</p> <p>i. G. Smith</p> <p>j. All</p>	<p>(2) Work continues on completing VISITS-VaCARES module and bringing last several hospitals online.</p> <p>(3) MCAD deficiency: See item 6b.</p> <p>(4) Working on submitting annual data for Title V FY 05 application/report.</p> <p>(5) In collaboration with DCLS, will submit annual data for the National Newborn Screening Report data by 4/30/04. Past reports are available online: <a href="http://genes-r-us.uthscsa.edu/resources/newborn/00chapters.html">http://genes-r-us.uthscsa.edu/resources/newborn/00chapters.html</a></p> <p>(6) Will be starting new contract renewal process for (a) genetic centers and (b) metabolic treatment centers.</p> <p>b. VASCAP</p> <p>(1) New Web site: <a href="http://fhsweb/sicklecell/">http://fhsweb/sicklecell/</a>.</p> <p>(2) The following publications are available online: <a href="http://fhsweb/sicklecell/pubssc.htm">http://fhsweb/sicklecell/pubssc.htm</a></p> <p>(a) “Sickle Cell Counseling Handbook With Fast Facts Patient Education Series”</p> <p>(b) “Yearly Report on Status of Sickle Cell Services in Virginia 2003”</p> <p>(c) Five Patient Education Series fact sheets.</p> <p>(3) Monitoring Adult Screening:</p> <p>(a) Alexandria and Fairfax 28% all screens with &gt; 1% trait identification</p> <p>(4) Case management conference held 3/5/04 was a success. Expected 60-70 participants—had 109:</p> <p>(a) 43% providers.</p> <p>(b) 37% clients, partners, parents.</p> <p>(c) 20% other.</p> <p>(5) Trait Follow-Up Activities:</p> <p>(a) Toll Free line to VASCAP</p> <p>(b) Develop material/letter.</p> <p>(c) Plan to work with VaGAC Newborn Screening Subcommittee on trait follow-up proposal.</p> <p>(6) Contract renewals for funding comprehensive sickle cell clinic contracts.</p> <p>c. DCLS: MCAD deficiency: See item 6b.</p> <p>d. VDH CDC VaCATPIP Grant</p> <p>(1) In processing of determining mechanism to implement prescriptive-level folic acid statewide to women who</p>
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			<p>have a child with a neural tube defect. Folic acid has been provided to one woman.</p> <p>(2) 20 VaCARES fact sheets have been completed and are available online: <a href="http://www.vahealth.org/genetics/pubsgp.htm">http://www.vahealth.org/genetics/pubsgp.htm</a></p> <p>(3) VaCARES interactive Web site has been completed: <a href="https://apps.welligent.com/pls/vacares/vacares.main">https://apps.welligent.com/pls/vacares/vacares.main</a></p> <p>(4) VISITS-Genetics Center module is underdevelopment for new case ascertainment at genetic centers: VCU, CHKD, UVA.</p> <p>(5) Statewide genetics conference to be planned this year.</p> <p>(6) In process of piloting a project on integrating genetics with Va. Early Hearing Detection and Intervention Program using VDH MCHB/HRSA Hearing Grant funds.</p> <p>e. VCU MOD Grant:</p> <p>(1) Final report based on survey is being prepared; executive summary and chapter 5 will be sent to VaGAC for review.</p> <p>(2) Year-2 grant will focus on (a) physician provider survey and (b) urban, suburban, and rural focus groups to assess quality of genetic services.</p> <p>f. EVMS</p> <p>(1) Hearing grant was approved but not funded, will reapply.</p> <p>(2) Suggestion made to contact Dr. Walter Nance.</p> <p>g. MOD</p> <p>(1) The following MOD Resource Center materials were distributed:</p> <p>(a) "Newborn Screening Tests"</p> <p>(b) "Sickle Cell Disease"</p> <p>(c) "Hearing Loss"</p> <p>(d) "Genetic Counseling"</p> <p>(2) The MOD "State Public Affairs Plan for 2004" was circulated.</p> <p>(3) A document that explains advocacy was distributed.</p> <p>(4) Virginia Council on Folic Acid is now being funded by the VDH CDC VaCATPIP grant. The Public Service Announcement "Folic Acid Message</p>
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			<p>with Lisa Collis, First Lady of Virginia” will be aired by 6/30/04.</p> <p>h. DMHMRSAS: Part C of IDEA</p> <p>(1) All unspent funds are gone, working on ways to finance the system, including General Assembly budget request.</p> <p>(2) IDEA was re-authorized, looking for ways to extend IDEA to the age of 5.</p> <p>(3) Recommendation made for Part-C/ DOE connection to come under a VaGAC work group.</p> <p>i. DOE: No report.</p> <p>j. Other: Parent Involvement</p> <p>(1) Discussion on ways to help parents becomes a part of VaGAC.</p> <p>(2) Suggested resources and models:</p> <p>(a) Early Intervention Cmt.</p> <p>(b) Partners and Policy Making, Va. Board for Persons with Disabilities</p> <p>(c) The Arc</p> <p>(d) Parent to Parent Network</p> <p>(e) Family Voices</p> <p>(f) Voices for Virginia’s Children</p> <p>(3) Decision made not to develop new parent training because there are sufficient parent training resources available. The challenge is how to make connection that parents need to advocate for genetics across all conditions and disorders.</p> <p><b>Plan:</b></p> <p>(a) <b>A. Schreiber</b> will work with members of the VaGAC Parent Subcommittee to develop a proposed “Parent Role on VaGAC” for distribution to members.</p>
10:45 to 11:00	<p>4. Updates: Virginia Genetic Centers</p> <p>a. EVMS</p> <p>b. UVA</p> <p>c. VCU</p> <p>d. RFP Northern Virginia</p>	<p>a. V. Proud</p> <p>b. B. Wilson</p> <p>c. J. Bodurtha</p> <p>d. S. Williams</p>	<p>4. Updates</p> <p>a. EVMS: VDH funding has helped support ongoing services. Recruiting another genetic counselor to handle anticipated increase in cases.</p> <p>b. UVA: Budget challenges, might get additional genetic counselor staff through cancer center. Recent workshop on low protein cooking was a success.</p> <p>c. VCU: Factor Foundation grant awarded (focus is hemophilia). A copy of a Power Point presentation on MCAD deficiency, which was developed by student, was circulated.</p> <p>d. RFP, which was discussed under item 3a(1),</p>

			is only for perinatal genetic services; therefore, there will be a gap concerning pediatric genetic services.
11:00 to 11:10	5. Review/Update: VaGAC Infrastructure, including membership (revised 9/29/03) (emailed 3/23/04)	J. Bodurtha with group discussion	5. VaGAC Infrastructure <ul style="list-style-type: none"> <li>a. Parent Involvement: See item 3j.</li> <li>b. Additional members: Va. Chapter of the AAP might be interested. VaGAC subcommittees encouraged to invite additional members where appropriate—see infrastructure outline for suggested representatives.</li> </ul>
11:10 to 11:50	6. Work Group Reports <ul style="list-style-type: none"> <li>a. State Genetics Plan</li> <li>b. Tandem Mass Spectrometry (MS/MS)</li> <li>c. Parent Involvement</li> <li>d. VDH Contractors</li> </ul>	<ul style="list-style-type: none"> <li>a. J. Bodurtha</li> <li>b. W. Andrews</li> <li>c. A. Schreiber</li> <li>d. S. Williams</li> </ul>	6. Work Group Reports <ul style="list-style-type: none"> <li>a. State Genetics Plan: New members might be added. Completing first assessment activities: see MOD Grant, item 3e.</li> <li>b. MS/MS: MCAD (medium chain acylCoA dehydrogenase) deficiency screening began 3/1/04, which involved DCLS acquiring three tandem mass spectrometers and additional personnel, training staff, sending announcements to all providers, and conducting 13 site trainings. In addition to MCAD deficiency, DCLS is using tandem mass spectrometry to detect phenylketonuria (PKU), maple syrup urine disease (MSUD), and homocystinuria. An audio-conference call with Dr. Tom Sullivan has been scheduled at noon to address concerns he has regarding repeat newborn screenings.</li> <li>c. Parent Involvement: See item 3j.</li> <li>d. VDH Contractors: See item 3a(6).</li> </ul> <p><b>Plan:</b></p> <p>(1) <b><u>S. Williams</u></b> will schedule an audio-conference meeting.</p>
11:50 to 11:55	7. New Business	S. Long	7. If need additional quantities of MOD materials, please contact Sara Long.
11:55	8. Next Meeting <ul style="list-style-type: none"> <li>a. Date</li> <li>b. Time</li> <li>c. Location</li> </ul>	J. Bodurtha	8. Next Meeting <ul style="list-style-type: none"> <li>a. Tuesday, October 5, 2004</li> <li>b. 10 a.m. – 12 noon</li> <li>c. DCLS</li> </ul>
12:00	9. Adjourn <sup>1</sup>	J. Bodurtha	9. Meeting adjourned at 11:45 a.m.

<sup>1</sup> Steering Committee members are asked to stay after the meeting to schedule their next audio-conference call.